Health and social care support for people with dementia

Dementia strategy: a review of the experiences of people with dementia in England and how health and care services are responding

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Foreword

It is more likely than not that we will either experience living with dementia ourselves or provide care for a loved one with dementia in our lifetime, and the number of people being diagnosed with dementia is increasing. The economic impact of dementia is forecast to rise from £42 billion to £90 billion in the next 15 years.

It is more important than ever that people receive a timely dementia diagnosis and good ongoing person-centred care and support across primary, secondary and adult social care. Family and carers need to feel supported, with their own needs being met to enable them to continue to care.

At CQC, we are determined to play our part in making sure that people with dementia receive care that is safe, effective, compassionate and high-quality.

Care for people with dementia often involves many different types of health and social care services. To improve people's experiences across these different services, it is essential to listen to the voices of people who use services, their families and carers.

Our report highlights many of the challenges faced by people with dementia and their family and carers. We highlight, in their own words, how a lack of respect, compassion and understanding in health and care can have a negative impact on their day-to-day lives.

Our report also includes many examples of health and social care services and systems that actively seek to understand the people they support and provide the right care and environment to improve the quality of life for people with dementia.

The efforts of these services, and other organisations, have helped to raise the profile of dementia and the importance of good care. What is needed now is a single definition of what good, joined-up dementia care looks like, which needs research and co-production. As the regulator for health and social care, we are in a position to help make this definition a reality.

This definition of good care must include the voices of people who face discrimination or disadvantage so that we can tackle inequalities and promote people's rights by improving the care, support and experience of people with dementia and their family and carers.

As an organisation, we are committed to improving care for people with dementia and their families and will be inviting the public, those with lived experience of dementia, providers, commissioners, academics and national stakeholders to join us on this mission.

James Bullion, Interim Chief Inspector of Adult Social Care and Integrated Care

Chris Dzikiti, Interim Executive Director for Operations and Executive Lead for Mental Health

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Summary

Dementia is caused by different diseases, including Alzheimer's disease and vascular dementia, which affect memory, thinking and the ability to perform daily tasks.

Misconceptions about dementia include that it is a 'natural' part of ageing. However, it also affects people under 65 and research suggests that almost half of dementia cases could be prevented.

The number of people being diagnosed with dementia is increasing. In February 2025, nearly half a million people in England had a dementia diagnosis.

The likelihood of developing dementia, becoming an informal carer or both in a lifetime in the UK is 55% (around 1 in 2).

The number of people with dementia is forecast to grow over the coming years, largely due to population growth and an ageing population, with estimates that 1.2 million people are expected to be living with dementia in the UK by 2040 (with some estimates even higher).

For this report we looked at what people were telling us, through surveys and feedback, about their experiences of living with dementia when using health and adult social care services, including the experiences of families and carers. We have set out the main themes that influence whether an experience is good or poor, and what health and care services are doing to improve these experiences.

We will use the findings in this report to help shape our work to define what good care looks like for people with dementia and inform the next phase of CQC's Dementia Strategy.

The impact of dementia

As described in this report, dementia is life changing for people living with it and those who care for them.

The economic cost is also stark. In 2024, the cost of dementia to the UK was estimated at £42 billion, and is forecast to rise to £90 billion by 2040. A high percentage of these costs are borne by people living with dementia, and their families and carers.

Dementia also has a significant impact on the provision of health and social care. For example, around two-thirds of care homes support at least 1 person with dementia, and in around a third of care homes, the majority of people supported have dementia.

Through our analysis, we found that care homes where more people had dementia were more likely to report staffing issues, which can prevent people from receiving high-quality care. In the care homes we looked at, as the proportion of people with dementia increases, staff-to-person ratios decrease, staff turnover increases, there are fewer qualified staff, and fewer staff have named supervisors. For example, there are 20% more staff per person in care homes where fewer than half of people have dementia than in those where most have dementia.

We encourage providers to submit notifications, as it demonstrates a culture of transparency and learning, and is linked with good care. However, our analysis of notifications found that care homes that support more people with dementia have a higher rate of adverse events:

- Care homes where a majority of people have dementia submitted more than twice the number of notifications of serious injuries per person compared with care homes that do not support people with dementia.
- Care homes where everyone is aged 65 and above, and the majority of people have dementia, submitted 75% more notifications of abuse or allegations of abuse per person than care homes where people over 65 with dementia are in the minority.

Access to health and care support

Although nearly half a million people in England had a recorded dementia diagnosis last year, the actual number of people living with dementia is much higher (figures from the Department of Health and Social Care estimate this to be over 700,000).

Diagnosis rates vary by region by nearly 10 percentage points – in the South West, 61.2% of people aged over 65 estimated to have dementia had a recorded diagnosis, compared with 70.1% in the North West.

People are waiting longer for their diagnosis. The average waiting time from referral to diagnosis increased from 124 days in 2021 to 151 days in 2023. Waiting times were affected by increased numbers of people being admitted to relevant services, while average staffing levels have not increased in accordance.

Through our surveys, people have also told us that they were having to wait too long for a diagnosis, and about a lack of ongoing care and support for dementia in the community.

> “There does not seem to be ongoing care for people living with Alzheimer's disease, or

> their carers. I have had to seek out community charity support groups. We have not seen a doctor, consultant or nurse on an individual basis for over a year.”

However, people who had good support from their primary care services during their dementia diagnosis described the positive effect this had on their wellbeing.

> “My GP has been an amazing facilitator and advocate for me while undergoing my assessments leading to my early onset dementia diagnosis. She has been supportive and understanding of my concerns and I know my diagnosis would not have been as timely without her.”

Through our engagement with adult social care providers, we have heard some good examples of how they are consulting and working closely with a variety of dementia support services and partners to share knowledge and provide specialist care to people with dementia.

To support people with dementia to get the best outcomes, it is important that local authorities and integrated care systems work with providers to consider the needs of people with dementia in their areas, and provide joined-up care.

Person-centred care

Understanding people’s care needs

People commenting in the 2022 Adult inpatient survey said that acute hospital staff do not always understand the specific care needs of people with dementia. The busy, often frenetic nature of the acute environment can lead to the needs of dementia patients being overlooked.

Similarly, our analysis of feedback about adult social care shows that often staff were not adequately attending to people’s day-to-day care needs. This included support with nutrition and hydration.

> “Dad was not encouraged to eat in the dining room which isolated him. Staff didn't encourage him to eat or drink. A water bottle had been in his room for two days, so his fluid intake was not monitored.”

On the other hand, people also told us how important a person-centred approach is for good care and support of people with dementia.

> “The main difference is that in hospital Mother was under 24-hour observation but with very little human interaction from the staff. Last week I visited Mother in the home and she was in the lounge quietly singing Christmas carols while one of the carers was giving her a head massage – who wouldn't thrive in an environment such as this?”

Adult social care services that support people with dementia recognise that everyone has a life story. Staff support people to maintain their routines and engage in the everyday activities that characterised their lives. They also recognise that dementia is a journey and people change medically and personally, so adapt their care and support over time.

Communication

Respondents to NHS hospital surveys often indicated that communication between staff and patients was poor, and family members and carers felt they were not consulted on their loved ones’ care and treatment. They also spoke of poor communication between services in discharge arrangements.

> “The lady was listed for hospital admission but because there were no beds was sent home by ambulance. She lives alone. The ambulance service did not put the heating on. The carers did not come for 12 hours post discharge and were unaware of changes to medication.”

The NHS hospital surveys also described positive experiences, where communication was tailored to meet people’s needs and that their dementia was ‘seen’ and adjustments were made. People described the way in which staff communicated with them as ‘patient’ and ‘kind’, and staff ‘respected’ people with dementia.

Some adult social care providers are exploring how they can improve communication with people with dementia using physical and digital tools. This includes technology to help assess pain for people who may not be able to verbalise it.

Our inspections also highlight steps to promote social interaction and understanding between visiting families and carers and people with dementia:

> “When you walked in, there was a corner where there were bags with lots of different games and activities for relatives to engage with their family member. And there was a poem on the wall that said, ‘I may not be able to remember what’s been said, but I'll always remember how you made me feel’.”

Environment

People with dementia often need a stable, familiar environment with people they know around them to reduce stress and support their wellbeing. This can be challenging in a busy hospital environment.

> “Mum was moved ward and became very confused and frightened. She volunteered to be moved but I don't think her dementia was taken into account.”

People also told us that their family members’ care homes did not support their overall wellbeing. For example, people’s bedrooms did not contain familiar objects or there was a lack of access to outside space.

Other care homes are adapting their environments to make them more ‘dementia friendly’ – helping people with dementia to be empowered, supported and included. For example, they have provided homely and calm spaces to support people with dementia. This included indoor and outdoor dementia-friendly garden spaces, dining rooms that encourage people to eat together, and spaces that stimulate the senses, like sound and lighting to enhance the natural cycle of day and night.

We have also seen the steps that some NHS hospitals are taking to improve the environment for people with dementia, including providing quiet waiting areas for people with dementia.

Keeping active

Keeping active and mentally stimulated is an important part of living well with dementia.

Responses to the Adult inpatient survey suggest that this can be difficult to achieve in a hospital setting. For example, one person said they were told mainly to stay in bed, while another was given a colouring book and left to “get on with it”.

We received similar comments about some adult social care services, with several people saying their loved ones were confined to their rooms with little or no contact with other people.

> “Dad was left to his own devices in his room alone. The staff either sat in the TV room on their phones, or in the dining room out the way. In 2.5 months I never saw any classes or therapy to help residents.”

Not engaging or interacting properly with people with dementia can lead to a deterioration in their overall health and wellbeing. It can also be the trigger for distressed behaviours that require additional staffing support.

Care services gave some positive examples of activities that seek to understand each person, often engaging the local community into the life of the care home.

> “We have been able to access dementia-friendly viewings at our local theatre which are a more relaxed performance where residents living with dementia can feel more comfortable.”

Staffing and training

Staffing

The pressures on the NHS workforce are reflected in what people told us. This includes loved ones being left alone for long periods with no one attending to them and relying on their family carer to have their needs met.

> “The hospital was clearly overwhelmed but there were things that could have been done better. For example, nobody seemed to check how much fluid patients were drinking nor how much they were eating.”

People also told us they were concerned about how low staffing levels could affect the quality and safety of adult social care for them or their loved ones – for example, people leaving their care home unexpectedly without staff knowing and being exposed to risk of harm such as falls, due to a lack of supervision.

Consistency in care staff was another issue that concerned some people. For people with dementia, being familiar with the people that care for them is important so they can build a relationship. It also helps staff understand what their needs and preferences are.

> “I was promised no more than 3 carers would visit my dad. But over 22 visits there were 15 different carers that visited. My dad would not be able to form a bond with so many 'strangers' as he called them visiting. How could they get to know him to provide adequate care? I didn’t feel the needs of my dad with his dementia were understood.”

Comments about adult social care suggest good care for people living with dementia is provided by well-trained, compassionate professionals who understand the person and how best to relate to them.

> “I recall on one occasion when visiting our mother, [staff member] arriving with a copy of the Racing Post for one lady who he then had a wonderful conversation with about the horses running that day.”

Recruitment

Adult social care providers have told us about the challenges they face in recruiting the right staff with the skills and experience required to support people with the care needs that can come with advanced dementia.

One of the ways they are tackling recruitment challenges is through expanding their use of social media, which has also improved occupancy and links with the local community.

Some providers included people with dementia in their recruitment and interview process. As well as being able to directly assess the dementia-specific skills of potential care workers, this can support people with dementia to engage previous life skills and to directly influence their care home.

Training

Data from Skills for Care highlights that only 29% of the care workforce in England have had any kind of dementia training.

Key stakeholders we engaged with for this work have identified a need for a clear baseline understanding of dementia for everyone who works in health and social care, at all levels.

Providers have recognised that staff need to improve their knowledge of effective dementia care. To address this, some adult social care providers have enrolled their staff on specific training.

> “In the past year we have continued our programme of experiential training (Virtual Dementia Tour). To ensure we embed understanding and empathy across the whole service, we have provided office team members, as well as frontline staff, with this engaging opportunity.”

Family and carers

Family and carers play an essential role in supporting people with dementia to remain in their homes, access services and to receive appropriate care and treatment.

Some family and carers felt there was an over-reliance on them for intervention and advocacy when their loved ones were using health and care services.

> “I am my husband’s carer and spent every day for at least 10 hours a day in the hospital. If I had not taken my husband to the bathroom and washed and cleaned him, he would have been in an awful state.”

Over time, the pressure of caring for someone with dementia, on top of other commitments, can take its toll on family and carers. Health staff describe situations where carers were reaching a tipping point.

> “His mum is the only carer, and she is becoming increasingly overwhelmed with caring for both her son and husband with young age dementia. His mum also has her own mental health issues.”

Family and carers told us that communication with staff and management could be poor, with calls and requests for meetings being ignored, or concerns not being addressed.

However, good dementia care ensures that carers are listened to and included in all appropriate care discussions.

For example, when a person with dementia goes into a care home, this can be at crisis point for families, so services that appreciate this and provide good dementia-aware care are vital.

> “The team have allowed us to be his family again. His wife is able to continue being his wife and his daughters able to be his daughters again, rather than his carers. So, we are able to appreciate and concentrate on the special moments we have left together.”

We also note adult social care services that provide space for carers to step back from their caring responsibilities and socialise with people with shared experiences.

> “We noticed there were quite a few family members that were really struggling… We set up a small group in a quiet lounge where we would give them afternoon tea once a month. Often the chat was nothing about dementia or their loved ones… went from introductions to actually, what was good on TV last night.”

Inequalities

Key stakeholders told us inequality was a root cause of issues facing people living with dementia. Persistent misunderstandings and stigma associated with dementia can also lead to inequalities in how care is delivered and commissioned. Inequalities are present from prevention through to people’s experience of living with the condition.

This is reflected in the Adult inpatient survey 2023, which found that people with dementia reported poorer experiences for almost all questions, including:

- being more likely to feel they were not treated with sufficient respect and dignity
- feeling less involved in their care

- being less likely to feel hospital staff took their individual needs into account.

When a person has dementia and also has needs related to another protected characteristic under the Equality Act 2010, such as other disabilities, ethnicity and sexual orientation, health and care providers and staff should be aware of a number of considerations that ‘intersect’ or have a combined impact with each other. For example, previous negative experiences of stereotyping or discrimination may be re-lived, or people may be confused about their gender identity.

However, we have seen limited consideration for the combined impact of dementia and other protected characteristics in the analysis for this report. Exceptions to this included:

- respecting the culture and preferences of a person with dementia to support them to eat well
- speaking to someone in their preferred or first language
- continuing to respect people’s religious beliefs, despite dementia impairing the ability of a person to always remember or practice their faith
- using toolkits and training to support people with dementia from ethnic minority groups and LGBT+ communities.

Our learning and next steps

What we have heard and learned

We are grateful to the contributions that people with lived experience, carers, professionals, providers and other national stakeholders have made to this work so far.

Several themes emerged from this engagement, as well as from the insights we have gathered from our regulatory work. We have also heard the call from other organisations like the Nuffield Trust, Alzheimer's Society and Skills for Care for national stakeholders to raise the national profile of dementia and work together on defining and implementing good practice in these areas.

These themes and insights from our engagement include:

Access to health and care support before and after a dementia diagnosis

A clear, accessible, easy-to-navigate pathway of care is needed. This should be joined up between social care, community care and other health services to enable seamless transitions between services, focusing on prevention and risk reduction.

Person-centred care and principles that respect and protect people's rights

This should be central to areas such as:

- planning and delivery of care
- consent and communication
- coordination of care between services
- equity of access to evidence-based treatments
- environmental adaptations
- safety alongside positive risk taking.

Health and social care workforce capability and competency

Consistent workforce skills, knowledge and values that reflect an understanding of dementia and delivering person-centred support is important.

Support for carers

Carers must be respected, supported, involved and listened to, and acknowledged for their expertise in the person they care for.

Inequalities and unwarranted variation

People and carers have very different experiences across health and social care depending on where they live, how their care is funded or their protected characteristics.

What we will do

The central vision statement of CQC’s Dementia Strategy is:

As a dementia-friendly and inclusive organisation, CQC uses its powers and purpose to tackle inequalities and promote and protect rights to improve the care, support and experience of people living with dementia and their carers.

To achieve this vision, our Dementia Strategy has 6 core objectives:

- We will co-produce evidence-based statutory guidance for what good dementia care looks like and link to good practice guidance under our assessment framework.
- We will apply the statutory guidance across our regulatory activity.
- We will use our independent voice to tackle inequalities and encourage improvement and innovation.
- We will be a dementia-friendly and inclusive organisation to benefit our staff and the wider public.
- Our staff will receive comprehensive dementia training and work with partners to influence training and competency for the health and social care workforce.

- We will actively work in partnership with key stakeholders to collectively affect real change.

What's next

Our next steps for progressing this work will be focused on the following areas:

Developing statutory guidance and defining good practice

We will work towards achieving objective 1 to develop statutory guidance. We will:

- involve people with lived experience, carers and a wide range of other stakeholders in co-production, ensuring the guidance is led by the voice and experiences of people who use services
- carry out research into the characteristics of effective dementia care, including learning from other countries and regulators, as well as further information gathering to develop a robust evidence base on which to build the statutory guidance principles.

Learning and development needs of CQC’s workforce

To ensure we are effective in our regulation of services for people with dementia, we will ensure that we understand and respond to the learning needs of our own staff in this area. This includes carrying out a learning needs analysis, defining learning objectives and developing training and guidance for CQC staff aligned to the statutory guidance we publish.

Engagement and communication

We will apply a wide range of tools and approaches to involve people, carers, key stakeholders and CQC staff in the development of this work. We will continue to work collaboratively with other key stakeholders and policymakers on joint improvement ambitions and actions that enable good dementia care, in areas like workforce, system pathways and technology. We will share updates on our work with the public, providers and other partners and share future opportunities to get involved.

Methodology and evidence used

In this report, we use evidence from our inspection activities with other information and personal experiences, including from people who use services, their families and carers, to inform our view of the quality of care for people with dementia.

We have collected bespoke qualitative evidence to understand the experiences of people with dementia. We have gathered views from our inspection and assessment teams, key stakeholders, subject matter experts and people with dementia and their family and carers to understand what it is like to access and experience health and social care while living with dementia.

We have also reviewed reports published by our stakeholders and analysed publicly available datasets to supplement our understanding of the challenges facing people with dementia and their carers.

People's experiences

People share their experience of health and care services with us through our online Give feedback on care service, and in the free text responses to our National Patient Survey Programme.

- We carried out a thematic analysis of a sample of 207 Give feedback on care comments relating to dementia between November 2022 to November 2023. The sample included comments from people using care homes, homecare and GP services. It did not include responses from people working in services.
- We analysed over 300 comments from people identified as having dementia or Alzheimer's disease and who had discussed dementia in the 2022 NHS Adult inpatient survey, 2023 NHS Urgent and emergency care survey, and the 2023 NHS Community mental health survey.

When people share their experiences through our Give feedback on care service they are consenting to giving us their feedback. We tend to receive more negative comments than positive comments from the public. People often include more detail in their negative feedback to us, which means we can say more about these experiences.

We also commissioned PPL, a management consultancy, to gather the experiences and case studies of people with dementia and their family and carers, from diagnosis through to end of life.

We analysed of a sample of 200 Learning from Patient Safety Events reported between June and December 2023 where people had referenced dementia. These events took place across the health and care system, from hospital to care in people's homes.

A view of providers

To identify common themes and examples of what good quality care for people with dementia looks like, we analysed:

- a sample of 16 inspection reports from care homes that had been rated as outstanding in 2023/2024 where most of the people supported were living with dementia

- 6 Mental Health Act reviewer reports about wards for people with dementia – these reports were shared with us because they included examples of good practice
- findings from 2 focus groups with inspectors.

We also analysed 14 local authority assurance reports and interviewed assessors to understand how local authorities were supporting carers and people with dementia in their areas.

We ask adult social care providers to submit a provider information return (PIR) form every year. As well as helping to monitor the quality of care, this asks the provider about any changes that have been made in the past 12 months and how they are ensuring their service is safe, effective, caring, responsive and well-led. We carried out qualitative analysis of 100 responses to 4 questions from PIRs of residential and community services that care for people with dementia and who had referenced dementia care in their responses. The PIRs were submitted between April 2023 and September 2023.

We have also included experimental quantitative analysis using our PIR and statutory notifications data. The PIRs used here were between April 2021 and March 2024 (13,725 in total), to enable us to review a larger sample and take the most recent available submission from providers:

- we used quantitative data from PIRs to estimate the number of people with dementia in each registered care home, the age of people living in the care home and the total number of occupied beds
- we looked at various staffing measures from the PIR including vacancy level, staff turnover, percentage of staff with a care certificate, average number of staff qualified at level 2+ and the average percentage of staff with a named supervisor and compared this with the proportion of people living with dementia in each care home

- we used the reporting of statutory notifications – particularly abuse or allegation of abuse and serious injury in care homes and PIR data on the use of restraint and restriction and compared this with the proportion of people living with dementia in each care home.

PIRs are collected through an online self-completion questionnaire and, while we have applied cleaning rules as part of our analysis, the returns are not validated and may be subject to data quality issues. These cleaning rules also mean that some PIRs are not able to be included in the analysis.

We also consulted widely with stakeholders to inform our report. We engaged with over 50 stakeholders with interests and expertise in the care and treatment of people with dementia between March and June 2024. The aim was to discuss CQC's dementia strategy and understand from their point of view what the key issues are facing dementia services, people living with dementia and their carers.

About dementia

What is dementia and how can it be prevented and supported?

Dementia is caused by different diseases, including Alzheimer's disease and vascular dementia, which affect memory, thinking and the ability to perform daily tasks.

Misconceptions about dementia include that it is a 'natural' part of ageing. However, it also affects people under 65 and research suggests that almost half of dementia cases could be prevented, for example by keeping active and managing hearing and sight loss.

Focusing on preventing sickness to help people stay healthy and independent for longer is 1 of the 3 big shifts to the way health and care services work in the proposals for the government's 10 Year Health Plan.

Care and support for people with dementia can be complex because of the high numbers of people living with dementia, and the variation in the symptoms each patient experiences.

The NHS and local authorities have statutory obligations to provide care for people with dementia, and support for unpaid carers, under the NHS Constitution, the Health and Care act 2022, the Care Act 2014 and the Carer's Leave Act 2023. There are also many voluntary, community and social enterprise organisations that provide services for people with dementia, their families, and carers. As outlined in the NHS Long Term Plan, collaboration between the NHS and the third sector is key for improving outcomes for people with dementia and their carers.

The term 'dementia friendly' is used in this report, which has been defined as "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential". We will continue to explore language used in this area, as part of our Dementia Strategy.

How prevalent is dementia?

The number of people being diagnosed with dementia in England is increasing. NHS England figures show that in February 2025, nearly half a million people in England (496,471) had a diagnosis. But the estimated actual number of people living with dementia is much higher (figures from the Department of Health and Social Care estimate this to be over 700,000).

Dementia was identified in Office for National Statistics figures as the leading cause of death in England and Wales in 2023, accounting for 11.5% of all deaths, with women being more affected than men.

A 2023 dementia in the UK study found that:

- the likelihood of developing dementia in a lifetime is 36.2% (around 1 in 3)
- the likelihood of becoming an informal carer for a person with dementia in a lifetime is 30.4% (around 1 in 3)
- the likelihood of developing dementia, becoming an informal carer or both in a lifetime is 55% (around 1 in 2).

The study also reported that the number of people with dementia is forecast to grow over the coming years, largely due to population growth and an ageing population. It estimated that 1.2 million people are expected to be living with dementia in the UK by 2040 (with some estimates even higher). This is a 30% increase from 2022.

The impact of dementia

The impact of dementia for people and their families can be profound. Around 40% of people with dementia experience mental health problems, like anxiety or depression according to a 2021 study. In 2024, the Alzheimer's Society published a survey that found that 75% of people who care or who have cared for a person with dementia reported experiencing at least one negative impact, with over half stating their mental and physical health had been negatively affected.

The economic cost of dementia for society is also stark. A 2024 report commissioned by Alzheimer's Society estimated the cost of dementia to the UK at £42 billion in 2024, and is forecast to rise to £90 billion by 2040. A high percentage of these costs (around 63%) are borne by people with dementia and their families. Health and social care costs amounted to around £24 billion last year.

But dementia can have a greater impact on some groups of people than others. The Major conditions strategy: case for change and our strategic framework, published by the previous government, highlighted the inequalities linked with dementia and acknowledges that more needs to be done to understand them:

> “We know that there are disparities in dementia. Some groups are more at risk of potentially preventable dementia than others and there are disparities in dementia diagnostic rates across the country. More research is needed into dementia risk factors, including disparities such as those that exist between different ethnic groups, by gender and by deprivation.”

Findings from our analysis of provider information returns

We reviewed the most recently available provider information returns (information that care homes are asked to send us annually) from active care homes that carry out the same regulated activity (providing accommodation for persons who require nursing or personal care), submitted between April 2021 and March 2024 (13,725 in total). Two-thirds of care homes (9,319) told us that they supported at least 1 person with dementia, and 1 in 3 (5,362) reported that more than half of the people they care for have dementia.

The provider information returns also indicated that care homes that support people with dementia tend to be larger than those that do not. While 83% of care homes that do not support anyone with dementia are small (supporting 10 or fewer people), only 3% of care homes where most people have dementia were this size. In contrast, 23% of care homes where most people have dementia are large (supporting 50 or more people).

To safely and effectively support people with dementia, care home staff need knowledge and skills, and providers need to ensure their staff have enough support and capacity. Failure to meet these needs may expose people with dementia to increased risks to their safety and human rights.

Despite this, our analysis of provider information returns found that care homes where more people had dementia were more likely to report staffing issues, which can prevent high-quality care. In the care homes we looked at, as the proportion of people with dementia increases, staff-to-person ratios decrease, staff turnover increases, there are fewer qualified staff, and fewer staff have named supervisors. For example, there are 20% more staff per person in care homes where fewer than half of people have dementia than in those where most have dementia.

Our analysis of provider information returns also suggests that care homes with a higher proportion of people with dementia may also be responding to staffing pressures through a greater use of restrictive practices.

We found that care homes where more than half of the people have dementia included restraint or restrictions in 37% of people's care plans, compared with 28% in homes where people with dementia are a minority.

Where restraint and restriction are not used as a last resort, this means that people's human rights are likely to be compromised.

Many people with dementia may also be deprived of their liberty in a care home and be subject to a Deprivation of Liberty Safeguards authorisation. As part of the National Preventive Mechanism we must take an approach as a regulator where we are preventing inhuman or degrading treatment for these people.

Findings from our provider notifications

Given these findings from provider information returns, we wanted to explore whether care homes that support more people with dementia have a higher rate of adverse events.

Registered providers must notify us about certain changes, events and incidents that affect their service or the people who use it. We encourage providers to submit notifications, as it demonstrates a culture of transparency and learning and is linked with good care.

We analysed a year of notifications up to September 2023 to investigate patterns in care homes supporting people with dementia. We found that:

- compared with care homes that do not support people with dementia, care homes where the majority of people have dementia submitted more than twice the number of notifications of serious injuries per person
- among care homes where everyone is aged 65 or over, care homes where the majority of people have dementia submitted 75% more notifications of abuse or allegations of abuse per person than care homes where people with dementia are in the minority.

Further analysis showed that large care homes supporting people with dementia are associated with a larger number of notifications per person. For example: among care homes where more than half the people have dementia, large care homes (supporting 50 or more people) reported 54% more notifications of serious injuries per person (as many as 1 for every 5 people) than small care homes (supporting 10 or fewer people).

The rest of this report details further challenges faced by people with dementia and their family and carers and what good support can look like.

Access to health and care support

What is the impact of issues in access to dementia diagnosis and support?

Diagnosis

In 2023, the Major conditions strategy described how a formal dementia diagnosis, as part of a dementia pathway, is important to help both people with dementia, and those supporting them, to access to care and support, empower them to manage their condition and plan for the future.

This is supported by the results of the 2024 Alzheimer's Society survey of people who are close to someone with dementia or living with symptoms, which found that almost everyone sees a benefit to receiving a dementia diagnosis: for 7 in 10 the benefit is being able to receive the right care, and for 6 in 10 it was about being able to plan for the future. Only 1% saw no benefit.

However, as highlighted by the strategy, “not enough people have access to an accurate and timely dementia diagnosis – with significant variation across the country.”

According to NHS England data, at the end of February 2025, 65.4% of patients aged 65 or over who are estimated to have dementia had a recorded diagnosis of dementia. This rate has gradually increased from 62.6% since October 2022. The previous dementia diagnosis rate target of 66.7% has been removed from the NHS Operational Planning Guidance for 2025/26.

Diagnosis rates vary by region – in the South West 61.2% of people aged 65 and over who are estimated to have dementia had a recorded diagnosis, compared with 70.1% in the North West.

Respondents to the 2023 NHS Community mental health survey said that they were having to wait too long between a referral and an assessment or diagnosis for dementia. This was supported by the 2023/2024 National Audit of Dementia, which found people are waiting longer for their diagnosis. In 2023, the average waiting time from referral to diagnosis increased to 151 days from 124 days in 2021. Factors affecting waiting times include increased numbers of people being admitted to relevant services, while average staffing levels have not increased in accordance.

The audit also flagged variations in diagnosis rates in memory assessment services. The proportion of patients in each memory assessment service who received a diagnosis of any type of dementia varies from 36% up to 100%, but for Alzheimer's disease (the most common subtype of dementia), this ranged from 6% to 90%.

Post-diagnosis support

Dementia care and support

The National Institute for Health and Care Excellence guidance on Dementia: assessment, management and support for people living with dementia and their carers covers person-centred care and support, tailored to the specific needs of each person with dementia.

It recommends that cognitive stimulation therapy (usually group activities and discussions aimed at improving cognitive and social functioning) should be offered to people living with mild to moderate dementia. However, the National Audit of Dementia found that, while 76% of memory assessment services could offer this therapy, only 31% of patients with a dementia diagnosis were actually offered it.

As with diagnosis, respondents to the 2023 NHS Community mental health survey told us that they were having difficulties accessing ongoing dementia care, support and advice, particularly in a crisis.

> “I have vascular dementia, which is slowly getting worse. I am 85 years old, live alone and need help.”

Some people described having to seek out alternative care because of the lack of follow-up or ongoing care.

> “There does not seem to be ongoing care for people living with Alzheimer's disease, or their carers. I have had to seek out community charity support groups. We have not seen a doctor, consultant or nurse on an individual basis for over a year.”

By contrast, some survey respondents were positive about the support they had received, having not faced delays to their diagnosis or follow-up.

> “It was very efficient from the first meeting. Testing was quick and the results were followed up with discussions and a follow-on plan. Following the initial discussions, I had an interview with a doctor who carried out further tests, discussed the results which were very encouraging and arranged a follow-up meeting in 6 months’ time.”

People also described facing a lack of help and support from their GP in comments from our Give feedback on care service. People described trying to get appointments, advice, a referral to a memory clinic and medication reviews and were finding this challenging. One person described feeling ‘abandoned’ by their GP practice and another spoke of a “lack of support during my mother’s dementia progression”.

> “I have been offered no lifestyle advice or treatment except the medication prescribed by the hospital, which is reviewed once a year. I feel like if there was things that I could do to improve my health someone should have told me.”

At a system level, we have identified gaps in dementia care provision in most of the initial assessments from our local authority assurance work.

We found that specific support and care services available to people with dementia varied across the authorities and there was no evidence of a consistent pathway of care and support. This lack of a dementia pathway was also highlighted as a gap in our conversations with stakeholders.

A lack of appropriate care placements for people with dementia had led some councils to place people out of area, which could make visits from family and carers more challenging. One area linked this to the high cost of care for people with dementia and increasing demand.

Extract from a local authority assessment report:

> “...there was a lack of services for people requiring complex dementia care. The demand for these types of services was increasing as people aged. This issue was compounded because the cost of care was high. Decisions about care placements were based on value for money, quality of care and people’s choice. However, staff told us often cost was a driver and, where people had complex needs, this often resulted in out of area placements.”

Other health and care services

Some respondents to our Give feedback on care service said they struggled to get appointments with their GP surgery. People with dementia may not be capable of directly contacting their GP and rely on family members to make appointments and interact with the GP on their behalf. People said that navigating the various systems when trying to get an appointment for a family member was not only difficult but also took up a lot of their time or didn’t fit with their other commitments.

> “I have to work full-time and am caring for my mum with dementia. It is so frustrating that you cannot complete an e-consult until after 9am and before 5pm. They should not be allowed to set time constraints on when patients can fill these in. If they don't want a huge amount of e-consults they should see patients or answer the phone.”

Adult social care services also told us through their provider information returns about the challenges they faced accessing services for people with dementia, including GPs, mental health services and dentistry, with assessments generally subject to long delays. They also talked about the impact this can have on people using their service.

Adult social care provider information return:

> “Trying to find a dental service is a barrier to good care. We struggle to find a dentist

> that will see a resident with dementia and being able to find a dentist that is available to come to the home is very difficult. We have recently taken a resident to the emergency dental service. This was a distressing experience for the resident and the dentist was unable to carry out any examinations.”

Our 2019 report, Smiling matters, describes the challenges people living in care homes face in accessing dental care. It highlighted how oral healthcare support can be an issue for people with dementia more generally; for example, care homes that cared for people with dementia were less likely to have an oral health section within care plans.

How are providers and systems tackling issues in access to health and care support?

As noted in the King’s Fund report, The role of integrated care systems in improving dementia diagnosis, getting a good dementia diagnosis requires many different parts of the health and social care system to work together effectively. The report identifies key enablers of improvement, including strengthening relationships between primary care, memory clinics and other services; public awareness-raising activities; and the introduction of new extended roles for GPs (for example, to improve diagnosis in care homes).

Comments in Give feedback on care illustrated the important role primary care can have in supporting people through their diagnosis of dementia.

> “My GP has been an amazing facilitator and advocate for me while undergoing my assessments leading to my early onset dementia diagnosis. She has been supportive and understanding of my concerns and I know my diagnosis would not have been as timely without her.”

This is supported by CQC's professional advisors who told us they had seen good examples of GPs offering proactive support to connect people with dementia to activities, groups, and services in their community to meet the practical, social and emotional needs. They also described seeing surgeries that are more flexible in their appointment and home visit arrangements for carers and patients with dementia.

Adult social care providers used their provider information return to share how they consult and work closely with a variety of dementia support services and partners to share knowledge and provide specialist care to people with dementia. For example, they consult NHS healthcare services to assist care home staff, including mental health teams, memory clinics, community psychiatric nurses, district nurses, dentists, and opticians.

Adult social care provider information return:

> “[We have] an optician who visits for regular eye tests, or more often if required. They provide a dementia-friendly service and offer insight into different visual impairments to help us to gain further understanding of how this impacts on a person daily.”

Providers also reported making referrals to specialist dementia services, including dementia outreach, dementia care home teams, dementia crisis teams, dementia specialist nurses, and dementia hubs. Several care homes also reported engaging with dementia care and research charities, including Alzheimer's Society for specialist support and guidance.

Adult social care provider information return:

> “He requires support from several multidisciplinaries, including the Dementia Team, Parkinson's Nurses, Macmillan Nurses, the Diabetic Nurse and the GP. Having an established relationship with the above allows us to access specialist care and advice as required.”

Being able to directly refer to these services was highlighted as being vital to address care needs efficiently, as the condition can change quickly.

Adult social care provider information return:

> “We work with the memory clinic and refer patients if there has been a cognitive decline, or their dementia is affecting their mood, behaviour or physical health. We recognise that dementia is a progressive condition, therefore it is important to ensure patients are on the correct medication and seen in a timely manner to adjust their treatments and care plans.”

Adult social care providers also told us how partnership working with other local services helped to ensure that people with dementia are supported to be safe.

Adult social care provider information return:

> “We have a client who has advanced dementia. She was often found wandering outside her home unsure as to where she was. We worked closely with the police and her social worker to put measures in place to keep her safe, such as fitting door alarms which alert the care line when she leaves her home.”

To support people with dementia to get the best outcomes, it is important that local authorities and integrated care systems work with providers to consider the needs of people with dementia in their areas, and provide joined-up care. We see through our discussions with system partners where local initiatives such as the ones below, often with the voluntary and community sector, can bring benefits to people, as well as efficiencies.

Voluntary sector providing local dementia support services to local people under one roof

A community hub run by a charity in Southern England brings dementia support services to local people under one roof. Services include one-to-one support and advice, diagnostic services operated onsite by the local NHS trust, therapeutic activities, respite care and support groups. The services are flexible, enabling continuity across the dementia journey as people's needs change.

An impact evaluation of their work (in partnership with a local university) demonstrated the difference it makes to people, but also cost savings:

- People with dementia who had access to the community hub had better quality of life and wellbeing.
- Carers and family members also had a better quality of life due to improved access to information and support.
- NHS and social care costs for people's care and support were on average over £400 lower for people with dementia who had access to the hub over a 3-month period compared to those without access.

Pilot programme to improve the care for people with dementia when they receive emergency treatment and to return them home faster

A pilot programme in the North West brought together acute and community services, as well as primary care, voluntary sector, social care providers and commissioners across an area.

One of the programme's key aims is to improve the care for people with dementia when they receive emergency treatment. This includes new wards for people with dementia and redesigning care pathways to try to return people home faster or even treat them at home if possible.

New ideas included:

- recruiting 5 exercise facilitators and a team leader to deliver light exercise programmes on hospital wards, focusing on enabling them to return home, building on their strengths and existing support networks
- holding regular multidisciplinary meetings to discuss how to support people with dementia at home to try and avoid hospitalisation
- turning part of a hospital ward into a space designed for people with dementia to help them keep active.

Initial outcomes for the programme included:

- people with dementia going home from hospital 5 days sooner
- around 50 people avoiding hospital and being supported at home
- only 4 re-admissions to hospital after 3 to 6 months, as opposed to 47 in the same time period before the programme.

Person-centred care

Understanding people's care and support needs

What is the impact of a poor understanding of care and support needs?

People with dementia may be less able to communicate their care needs, so may be reliant on family and carers to advocate for them. We saw this happening in feedback we received across all care settings. However, not everyone will have someone to speak up for them.

Analysis of comments from the Adult inpatient survey indicates that acute hospital staff do not always understand the specific care needs of people with dementia. The busy, often frenetic nature of the acute environment can lead to the needs of dementia patients being overlooked.

> “Being the wife of [the patient], I did feel that doctors and nurses did not fully understand patients with dementia. I realise this was not a purely dementia ward, but felt a little more understanding should be given.”

Understanding that people with dementia may have continence issues was also lacking in some cases. The typically long waits in the emergency department (A&E) meant people needed to use the toilet during their visit. However, sometimes this was not prompted by staff and those who needed or requested support to use the toilet did not always get it.

> “The worst thing was she was asking, then begging, then crying for the toilet, ended in wetting and soiling herself.”

Continence care was also raised as an issue in adult social care, through Give feedback on care. People highlighted cases of people with dementia being left for several hours in wet pads or people having long waits to be helped to the toilet and therefore soiling themselves.

> “I actually went into the bedroom to see mum slumped on the edge of the commode,

> not sat on it correctly. She had actually urinated on the bedroom carpet due to incorrect positioning on the commode.”

These issues clearly have a strong impact on people’s right to privacy and dignity, but could also create wider risks around infection control and tissue viability concerns, as some people suffered skin damage.

People with dementia are often not able to deal with their everyday needs without support. Give feedback on care respondents also said that often adult social care staff were not adequately attending to people’s day-to-day care needs. This included support with nutrition and hydration.

> “Dad was not encouraged to eat in the dining room which isolated him. Staff didn't encourage him to eat or drink. A water bottle had been in his room for 2 days, so his fluid intake was not monitored.”

Other negative comments included making sure food is appetising, appropriate and in reach of people. We also received comments about not monitoring weight and people being left in food-stained clothes.

Poor nutrition represents a serious risk to the overall health of people. We were told of examples of people becoming dehydrated, rapid weight loss and requiring hospital care.

What demonstrates a good understanding of care and support needs?

In contrast to the issues raised above, positive feedback to our Give feedback on care service shows how important a person-centred approach is in providing people with dementia with good care and support.

> “Mum is quite a quiet person and loves that she can choose to eat in her room or downstairs. For the first week or so Mum ate all meals in her room but the team

> encouraged Mum to go down to lunch, which she now really enjoys as she is getting to know others, but appreciates having her breakfast and tea in her room.”

Everyone has a life story and the adult social care services that support people with dementia well recognise this. In these services, we found that staff support people to maintain their routines and engage in the everyday activities that characterised their lives. For example, an inspector described seeing one woman going around her care home cleaning, as that made her happy; for others their routines included going for a morning walk or checking the post – whatever it takes to maintain a sense of ‘self’.

Relationships and family life are likely to be a part of a person’s sense of ‘self’. Services, particularly in adult social care, that understand the importance and impact of this can support people to handle the life changes that dementia can bring for both the person and their family.

Adult social care provider information return:

> “A resident with advanced dementia has a key worker that buys anniversary, birthday cards and flowers so he can give them to his wife when she visits on these special days. This has had a positive impact on her emotional well-being as she has suffered from ‘guilt’ because she was no longer able to care for him herself in their home.”

Findings from our inspections of outstanding services also highlighted where staff understood people’s personal histories and used this to adapt to their care and support.

Adult social care providers tell us about how they consider the whole person when thinking about the needs of people with dementia. This includes, for example, considering the age of the person with dementia when planning their care.

Adult social care provider information returns:

> “We support a person who is around 60 years old and has dementia. She does not recognise that she has the condition and is fiercely independent and very particular about the staff who support her. She does not like to be supported by staff who are very young as she feels that she is 'old enough to be their mother' and that she does not have things in common to talk about.”

> “You have to consider age and abilities when supporting individuals living well with dementia. For example, individuals can believe they can still play football as they did regularly at a much younger age. Clearly, that is not possible, but it doesn't mean they can't play football, so this needs to be planned and arranged so they can still enjoy the experience.”

Our focus groups with CQC inspectors discussed how good and outstanding dementia care happens when services recognise that dementia is a journey and people change medically and personally over time. As a result, care needs to adapt to reflect the changes in people’s circumstances. One example was given of a person living in a care home who liked to be up and about at night, despite not having a history of night shifts or similar. Rather than insist on a ‘normal’ routine, the staff would sit with her and do creative things – making the most of the quiet and space.

We have seen above how incontinence, associated with dementia, can have a real impact on people’s dignity, as well as their health and wellbeing. Inspectors have highlighted in inspection reports of care homes that care predominantly for people with dementia, how staff can be committed to promote people's independence and dignity. For example, one person living at a care home was reluctant to take a medicine to resolve constipation because they’d had a bad experience in the past and feared being left in an undignified situation. Care plans showed how staff had sensitively reassured and guided the person in the importance of symptom management and the support staff would offer them. This is one example of care staff considering people’s previous experiences to ensure the people in their care were treated sensitively and with dignity.

Communication

What is the impact of poor communication?

Effective communication is a central element of good dementia care. This includes communication between professionals to enable joined-up care, and between health and care staff and people with dementia and their families and carers. Respondents to the Adult inpatient survey often indicated that communication between staff and patients was poor, and family members and carers felt they were not consulted on their loved ones' care and treatment.

Respondents also said they felt communication between staff was poor and they felt they were given conflicting information, which increased their concerns around the treatment people were receiving.

The importance of good communication and the effect of poor communication was also expressed in the Urgent and emergency care patient survey. For example, one respondent told us how it seemed staff felt communication wasn't necessary due to their mother's dementia, while another said decisions were taken without proper explanation. Others said staff didn't seem to realise they may not be understood or appeared to lack time to be sympathetic or patient.

> “The people treating him didn't know how to communicate and shouted at him and pulled him about causing distress. I intervened on several occasions. We were left for long periods of time with no explanations.”

> “I kept saying I need to be with my mum. She's not been out of the house on her own in years, but no one would listen. I was upset as well.”

There were also examples in the Urgent and emergency care survey of people being asked to make decisions they couldn't consent to and a reliance on carers to explain things or communicate on their behalf.

Respondents to the Urgent and emergency care survey also spoke of poor communication between services in discharge arrangements, which may have been assessed as unsafe if the person’s dementia diagnosis was properly considered. This included people being discharged home to empty houses or without appropriate care packages in place, and not informing carers they were ready to come home.

> “The lady was listed for hospital admission, but because there were no beds was sent home by ambulance. She lives alone. The ambulance service did not put the heating on. The carers did not come for 12 hours post discharge and were unaware of changes to medication.”

Poor communication between services and staff was also seen to have an impact on medicines management for people with dementia. Any changes to medicines need to be communicated between professionals, especially between services and in the community, as people with dementia may have difficulty remembering these changes or what medicines they have taken.

Families also raised concerns through Give feedback on care that adult social care staff did not always recognise that people with dementia may not always be aware that they require the attention of a doctor, or be able to communicate how they are feeling. This could mean that people were not receiving medical care or treatment in a timely and effective manner.

> “By the afternoon my mother's condition had deteriorated such that my sister, a trained nurse, assessed her condition as an emergency while she was visiting the care home. Eventually an ambulance was called by a GP who was on site. Senior staff and management at the care home failed to recognise a serious clinical situation that needed an emergency response. The ambulance very quickly diagnosed a probable hip fracture – within minutes.”

What supports good communication with people?

Positive responses received in the Urgent and emergency care survey highlight the importance of good communication. They described experiences where communication was tailored to meet people’s needs and where their dementia was ‘seen’ and adjustments were made.

People described the way in which staff communicated with them as ‘patient’ and ‘kind’, and staff ‘respected’ people with dementia. One carer described how the hospital had contacted her and the occupational therapy team involved in the person’s care and shared all the information needed.

> “You seem to realise that a patient with dementia needs to be reassured. [Person’s name] was taken through A&E into a small back ward to be assessed and treated. Wow, well done everyone involved and thank you NHS for working hard to improve your services even when under such pressure. It made my time less stressful.”

> “My experience [at hospital] was nothing but first class. The staff understood my panic. I did not have to explain my wife's dementia. My wife needs my full-time help. When we got into A&E the reception and staff were absolutely brilliant. My stress levels dropped. I was relieved. My wife was treated in less than 1 hour.”

As reflected above, comments received through our Give feedback on care service describe the challenges people often face when contacting GP services and how these are heightened when having to advocate for someone with dementia.

However, we also received positive comments that illustrate the difference that good communication and treatment from GPs can make to people with dementia and their families and carers.

> “My husband has been recently diagnosed with Alzheimer's. I feel the GPs took my concerns seriously when we first approached them with vague symptoms. The receptionists are professional and discreet, but also friendly and approachable.”

In our focus groups for this report, one inspector highlighted an example of good communication at a care home, which promoted social interaction and understanding between visiting families and carers and people with dementia.

Quote from an inspector during a focus group:

> “One provider used communication packs. When you walked in, there was a corner where there were bags with lots of different games and activities for relatives to engage with their family member. And there was a poem on the wall that said, ‘I may not be able to remember what’s been said, but I'll always remember how you made me feel’. When I spoke to the family members, they told me what a difference those packs had made and how they really helped to aid communication.”

Some adult social care providers are exploring how they can use physical and digital tools to improve how they communicate with people with dementia. This includes technology to help assess pain for people who may not be able to verbalise it. This pain assessment technology has been seen to demonstrate a greater quality of life for people, as well as a decrease in the use of antipsychotic medication.

Adult social care provider information return:

> “Currently, new systems are in the process of using [the digital tool] which aims to assess residents who cannot reliably verbalise their pain. Facial expressions are more intense and more frequent with people living with dementia as they have lost 'learn behaviours.”

Providers have also been using Talking mats, which is a digital screen with pictures to help people communicate when they find speaking difficult. Different packs of images can be purchased that relate to particular activities, so there is a cost associated with using this tool.

Adult social care provider information return:

> “Talking mats are completed and shared at the monthly residents’ forum and are also used in gaining feedback for surveys. This means we can gain the views of people living with dementia or communication needs where they have not had a voice before.”

Environment

What is the impact of a poor environment?

People’s comments in the Urgent and emergency care survey expressed how a busy and noisy department could be very distressing for people with dementia. People described becoming very ‘agitated’ ‘anxious’ and ‘confused’, sometimes forgetting why they had come to urgent and emergency care (A&E). One respondent described how their mother returned home “very distressed, exhausted and [the experience] took a huge toll on her.”

People with dementia could not always understand why they had to wait so long, found it difficult to sit still or be comfortable and didn’t understand why they needed to see so many people. Carers told how this could be very difficult to manage, especially when help and information was difficult to obtain.

Respondents to the Adult inpatient survey indicated how people with dementia often need a stable, familiar environment with people they know around them to reduce stress and support their wellbeing. This can be challenging in a busy hospital environment.

> “Mum was moved ward and became very disorientated. She was very confused and frightened. She volunteered to be moved but I don't think her dementia was taken into account.”

Analysis of hospital patient safety events notified to us shows that, for some people, anxiety and confusion can trigger aggression and this can result in staff using physical and chemical restraint.

People also used Give feedback on care to report that their family members were in care home environments that did not support their overall wellbeing. For example, people's bedrooms did not contain objects they were familiar with, or there was a lack of access to outside space because rooms for people with dementia were on upstairs floors.

What supports a good environment for people?

Through the provider information returns, care homes told us how they are adjusting their environments to provide homely and calm spaces to support people with dementia. The most common adaptation was improved signage, which aimed to help people orientate themselves in the home. In line with Alzheimer's Society guidance on making homes more dementia friendly, signs used appropriate colours and pictures to symbolise rooms.

Other changes included adaptations such as falls sensors, indoor and outdoor dementia-friendly garden spaces, dining rooms to encourage people to eat together, and spaces that stimulate the senses, like sound and lighting to enhance the natural cycle of day and night (circadian rhythm lighting).

Adult social care provider information returns:

> “We are in the process of making our upstairs lounge into a sensory room and have obtained some equipment for residents with dementia that includes specific lighting, music and tactile objects. The sensory room is to benefit people with dementia by providing a stimulating but calming environment, promoting socialisation, and improving mood.”

> “We maintained our indoor garden on the dementia residential area, which gives our residents the outdoor experience of being outside in the garden.”

Homecare and care home services are using signs and assistive equipment to prevent harm, as well as prompt daily tasks, including eating and drinking.

Adult social care provider information returns:

> “We have requested a door and floor motion sensor and GPS tracker in case she wonders off while attending day provision.”

> “With some clients with dementia, we have organised large, laminated notices to be pinned up to remind them of things. These include reminders for medication where we are not administering the medication; reminders for when carers will be visiting; our office contact number; contact numbers for family and friends; reminders to have food and fluids; and other pertinent information which they need to have but may forget.”

> “We have in situ a talking clock that alarms when the lady needs reminding of a certain activity, for example time for lunch, take medication, going and getting up from bed. This is currently working well for her.”

Extract from a CQC inspection report:

> “The service had recently signed up to a pilot to improve practices around supporting people with additional hydration needs. This involved a cup and saucer that could electronically measure how much had been drunk and upload this data onto their care records. Staff and other healthcare professionals could then accurately monitor how much a person was drinking throughout the day and offer more support if required.”

Making positive adjustments to the environment was also highlighted by our Mental Health Act reviewers during their visits to hospital wards for older people and those with dementia. Reviewers described services using evidence-based design principles, such as those referenced by the Dementia Services Development Centre.

Extract from a report from a Mental Health Act monitoring visit:

> “The wards incorporated many recommended features for a dementia-friendly environment including the use of contrasting colours in bathrooms and for handrails, different coloured zones as orientation cues, natural light, low stimuli, attractive homely features and a lack of clutter.”

Our 2014 thematic review, Cracks in the pathway, looked at the care of people with dementia receive as they moved between care homes and acute hospitals. Through this review, we saw how some urgent and emergency (A&E) departments had considered how confusing, noisy and disorientating the emergency department could be for patients with dementia. We have continued to see the measures that NHS hospitals are taking to improve the environment for people with dementia.

Extracts taken from a CQC inspection report of an NHS trust hospital:

> “The trust had placed significant emphasis on meeting the needs of people with dementia. In the outpatient department, quiet waiting areas for patients with dementia were provided. In the emergency department, patients were cared for in dementia-friendly cubicles, designed to create a calming environment. A ward was made dementia friendly and used activities, research and unique software to enhance the patient experience. This was prompted by a patient’s story at a board meeting.”

During a focus group, one of our inspectors talked about an innovative example where a care home had developed a partnership with a charity film production company to put together a film of each resident’s life set to a soundtrack of their favourite music. The inspector described, while being “in the office a lady was outside, clearly distressed. She came into the office. They put on the film for her on a tablet computer, and within 30 seconds she’s a different person. She’d gone from distress, didn't know what was going on to, ‘Oh I remember doing this and I remember doing that’ and it was quite incredible to be honest.”

Keeping active

What is the impact of a poor approach to keeping active?

Keeping active and mentally stimulated is an important part of living well with dementia. Keeping active can also help reduce the risk of developing dementia.

People's comments from analysis of the Adult inpatient survey indicate this could be difficult to achieve in a hospital setting. There was a lack of understanding from acute hospital staff around the specific needs of people with dementia, which affected the quality of their care and treatment.

Respondents recounted how they were left alone for long periods with little or no stimulation. One person said they were told mainly to stay in bed while another was given a colouring book and left to "get on with it".

> "No stimulation was provided to the patients – they were just left on their own for most of the day which would have been very confusing for patients with dementia in particular."

Keeping people appropriately active and stimulated while in hospital is important to help prevent their physical and mental health from declining and avoid delayed discharge. This is particularly important considering that Alzheimer's Society's report on health metrics calculates that people with dementia stay over twice as long for acute inpatient care compared to patients with similar characteristics that don't have dementia, particularly for unplanned admissions.

Feedback from adult social care providers through their information returns told us that person-centred activities were provided within dementia-friendly environments. However, this was not reflected in many of the comments received through Give feedback on care. Several people told us that their loved ones were confined to their rooms with little or no contact with other people.

> "Dad was left to his own devices in his room alone. The staff either sat in the TV room

> on their phones, or in the dining room out the way. In 2.5 months I never saw any classes or therapy to help residents.”

> “Staff are never available to take mum outside for fresh air and she is confined to her room.”

Failure to properly engage and interact with people with dementia can lead to their overall health and wellbeing deteriorating, and also be the trigger for distressed behaviours that require additional staffing support.

What supports a good approach to keeping active?

Understanding each person means that services can tailor activities to meet the needs of people with dementia.

In their provider information returns, adult social care services gave examples of different activities for people, including specific activities for those with dementia. This included outdoor activities such as gardening. A small number of services described creating dementia-specific opportunities for people to get out into new environments and socialise.

Other activities that providers said they supported people to attend included:

- dementia-friendly film and theatre screenings
- Alzheimer’s Society events, like tea parties and community lunches
- men’s shed and allotment visits for people with dementia
- connecting with local primary school or local school productions
- trips to dementia-friendly coffee mornings
- producing a newsletter with activities that people with dementia are encouraged to complete

- visiting the local library
- choir for people with dementia
- dementia-friendly swimming lessons.

Care services gave some positive examples of activities that engaged the local community into the life of the care home, which is important for inclusion.

Adult social care provider information returns:

> “We have built strong links within the community to ensure that our residents are engaged with community groups. The men’s shed now host a monthly session where men with dementia can enjoy socialising and activities. We are also now a donation point for the local foodbank. Work is underway for two of our team to be trained to host ‘singing for memory’, which means we will be able to invite both our residents and residents from the community to participate in this. We have also worked on intergenerational lifestyles and have a playgroup who visit the residents once per week.”

> “Friendship Café is held monthly. Mainly aimed at carers, to give them some relief, they can bring the person they care for if they wish. A chance for coffee, cake, a chat with others in similar situations to themselves.”

As described above, in care home environments often the most effective activities are person-centred and tailored to the individual, supported by life story work to understand people’s histories. This could be as simple as helping with laundry or working with the handyman.

A few providers were able to demonstrate the positive impacts of these person-centred approaches – for example “a reduction in the use of antipsychotic medication, improved appetite, increased activity levels, and decreased number of infections and falls.”

Staffing and training

What is the impact of workforce issues and pressures?

Capacity

The pressures on the NHS workforce are well documented, and this is reflected in the Adult inpatient survey. Respondents reported poor experiences in the oversight and care from staff during their hospital stay, saying they or their loved ones were left alone for long periods with no one attending to them and relying on their family carer to have their needs met.

> “He'd been in [A&E] for more than 8 hours by then waiting for surgery for a broken hip. He waited almost 50 hours for a bed in the ward to become available…. Plus the 12 hours he'd been on a trolley at [service name] (wetting himself and unable to communicate).”

> “Shocked to find my father (late stage vascular dementia) lying naked in A&E shouting ‘help me’ …. and being completely ignored by staff. He’d had no food, no regular meditation (usually on anxiety meds for vascular dementia).”

Staff used Learning from Patient Safety Events to record low staffing levels having an impact on their ability to monitor people with dementia, which in turn put patients at risk of wandering, falls, or other risks to themselves or others.

We were also told about issues with capacity in adult social care through Give feedback on care. Comments received highlighted concerns that low staffing levels could affect the quality and safety of care for them or their loved ones. People reported that they had visited family members in a care home and found it difficult to locate a staff member, with people left alone, distressed and wandering and exposed to risk of harm, such as falls. There were instances reported of people leaving their care home unexpectedly without staff knowing, due to a lack of supervision, with one person reported to have exited out of a window, with another walking out of the care home through an open door.

Similar issues were reported for homecare services. People said that care staff could turn up late to appointments, did not fulfil the contracted time for care and missed agreed appointment times.

Consistency in care staff was also raised as an issue. It is important for people with dementia to be familiar with the people who care for them so they can build a relationship with them. It also supports staff to understand what their needs and preferences are.

> “I was promised no more than 3 carers would visit my dad. But over 22 visits there were 15 different carers that visited. My dad would not be able to form a bond with so many ‘strangers’ as he called them visiting. How could they get to know him to provide adequate care? I didn’t feel the needs of my dad with his dementia were understood.”

Recruitment

Challenges in recruiting staff was a theme emerging from our analysis of provider information returns. Concerns included a reliance on overseas workers, for whom the recruitment process can be lengthy and complex, and the rising costs of transport, particularly for homecare.

Providers say there can be further challenges in being able to recruit people who have the appropriate level of skills required to care for people with dementia.

Adult social care provider information return:

> “We have seen an increase of dementia residents looking for placement, and an increase of needs for the current residents living with dementia. Fortunately, we have recently allocated 2 members of the team as Dementia Leads, who will attend focus groups to improve the experiences for our residents.”

Training

The Alzheimer’s Society report, Because we’re human too, describes why good quality, evidence-based, consistent dementia training for care workers matters. Despite the prevalence of dementia in the adult social care sector, as demonstrated in our notifications data above, the report highlights Skills for Care data that only 29% of the care workforce in England have had any kind of dementia training.

The National Audit of Dementia also identified staff training as an area for improvement. It found that 42% of hospitals were unable to provide figures for staff working on adult wards who had received dementia training at Tier/Level 2.

Key stakeholders we engaged with for this review identified that there is a dementia skills and knowledge gap across the health and social care workforce, linked to a lack of training. They indicated that even some senior staff do not understand dementia well. As a result, they can themselves be a barrier to good pathways to diagnosis and post-diagnosis support. They identified a need for a clear baseline understanding of dementia for everyone who works in health and social care, at all levels.

The dementia skills gap was echoed by people with dementia, their families and carers through the Adult inpatient survey. For example, one person said:

> “Dementia training needs to be vastly improved. Asking questions of dementia patients doesn't work – i.e. "Can I take your blood pressure?" Also drinks and food should not just be left on tables. Dementia patients are not aware they are there. More and better training.”

Similar sentiments were gathered through Give feedback on care regarding adult social care:

> “My mum was with this care provider, our experience with this company was awful the majority of the time. It was evident to see that in some cases very little training had taken place. One carer told me she'd had no training and did a few shifts shadowing carers then was just left to it – her words not mine.”

The importance of having the right knowledge, skills, values and behaviours to work in adult social care is highlighted in Skills for Care’s Workforce Strategy for Adult Social Care in England. This recommends that, “All workers should have dementia training aligned to the Dementia Training Standards Framework and roles within the Care Workforce Pathway”. The Care Workforce Pathway in turn sets out that “someone working in a dementia setting will need to have dementia care knowledge and skills”.

What supports a good approach to staffing and training?

The positive impact of good staffing

Give feedback on care comments about adult social care suggest the best care for people with dementia is provided by well-trained professionals who understand how best to relate to people who have dementia or similar conditions.

Although it is encouraging to receive positive feedback from family members and carers about their loved ones’ care, it should be noted that often they are describing the sort of care and support that people should be able to expect.

> “Mum is always clean and well kempt whenever we visit. Her clothes are clean and she is bathed and her hair washed regularly. The menu is updated every day and we can see the meal choice she has. She is never hungry or thirsty and she has gained weight (which she needed) since her stay.I am so impressed with the staff that look after her. They are patient and kind and spend time chatting to her even though they probably have very little understanding of what she is saying. They encourage her to keep mobile and to get involved in regular exercise and entertainment sessions. I sense that there is a real bond between them.”

As described above, consistency in care staff is important for people with dementia and helps staff to understand people’s needs and preferences. This enables them to provide person-centred care that takes the specific needs of each person into account, in a caring and compassionate manner.

> “At first there was a number of different ladies calling on Mum but now as she's advanced in her disease we have the same few ladies calling on her. We feel that this is greatly helping her condition. Mum has gone from being unsure of the carers calling on her to now welcoming them in, even watching and waiting at the window for them to call.”

Improvements to recruitment

Adult social care providers used their information return to share with us how they are tackling the recruitment challenges described above. This includes, for example, the increased use of social media.

Adult social care provider information return:

> “Most of the residents at [care home] are living with dementia and require specialised care and support from staff that know them and the residents are able to build a good rapport with the staff in return. With such high use of agency, we can sometimes miss

> the little things that matter, which was why a recruitment drive using social media and word of mouth was so important. We have employed over a dozen new members of staff. I have seen an improvement in staff morale and shift coverage. With our expanding social media, we have had an increase in occupancy, recruitment and our links with the local community have improved. The level of care the residents are receiving is higher than it was; care was always good but is now improving to be more holistic.”

Some providers included people with dementia in the recruitment and interview process. As well as being able to directly assess the dementia-specific skills of potential care workers, this can support people with dementia to engage previous life skills and to directly influence their care home.

Adult social care provider information return:

> “Residents are involved in staff recruitment by suggesting specific questions to ask the candidates. This provides a wide range of features to promote engagement, communication, and person-centred care to make the delivery of daily tasks more effective and enjoyable.”

Improvements to staff training

Providers have recognised that staff need to improve their knowledge of effective dementia care. To address this, some adult social care providers have enrolled their staff on specific training.

Adult social care provider information return:

> “We have introduced training support from a registered mental health nurse to support staff with information and training specific to people with dementia. Staff have worked on encouraging positive distraction techniques.”

Our inspectors reflected on the benefits of experiential training, when combined with skills-based training, with one saying, “Staff were passionate about this and told us how they had increased their understanding of people. Staff had changed the way they approached people, always introduced themselves and were aware to minimise unnecessary, startling background noises such as doors slamming.”

Family and carers

What are the challenges faced by family and carers?

According to the Dementia Carers Count charity, there are nearly 1 million families caring for someone with dementia in the UK, with numbers expected to grow. This can be challenging, emotional and take a physical toll. Many carers feel isolated and alone. However, family and carers play an essential role in supporting people with dementia to remain in their homes, access services and to receive appropriate care and treatment.

Our findings showed how some family and carers felt there was an over-reliance on them for intervention and advocacy when their loved ones were using health and care services.

Findings from the Urgent and emergency care survey, for example, described how carers intervened on their loved ones’ behalf to ensure they received food and attention, and that care and treatment was properly explained.

> “It was essential I was there, I was his voice.”

Carers and family members reported through the Adult inpatient survey that it was often they who had to take the lead in the personal care of the person in hospital, often with little support from the medical staff. This regularly left them stressed.

> “I am my husband’s carer and spent every day for at least 10 hours a day in the hospital. I was refused food and drink on the ward and no account of why I was there was taken. If I had not taken my husband to the bathroom and washed and cleaned him, he would have been in an awful state.”

Family members and carers also used our Give feedback on care service to describe having to step in to meet the needs of their loved ones when speaking about an adult social care service, saying that care workers apparently lacked the skill and compassion.

> “Clients do not have regular hygiene needs met. My father sleeps in his clothes and the family do all of his basic needs. Staff have a poor understanding of dementia and how to meet needs.”

The environment of the urgent and emergency care (A&E) department was challenging for carers as well as people with dementia. Carers described in the Urgent and emergency care survey uncomfortable and insufficient seating, or having to stand or sit on the floor as there was nowhere else. The long waits meant they found it difficult to leave to use the bathroom or get a drink, concerned the loved one would wander off or miss being called.

> “The room in A&E was next to a fire exit so I was unable to leave her even for the toilet due to her wandering and ripping out her cannula. I didn't eat or drink anything for over 26 hours as I had to remain by her side. I had a stool (no proper chair) to prop on all night while she slept and was freezing cold.”

Over time, the pressure of caring for someone with dementia, on top of other commitments can take its toll on family and carers. Learning from Patient Safety Event data records health staff describing situations where carers were reaching a tipping point.

> “His mum is the only carer, and she is becoming increasingly overwhelmed with caring for both her son and husband with young age dementia. His mum also has her own mental health issues.”

Despite the important role of family members and other unpaid carers in supporting people with dementia, people told us through Give feedback on care that communication between staff, management and family members could be poor. Examples included calls and requests for meetings being ignored, or concerns not being addressed. We discuss this issue more fully in the section in this report on communication.

> “Mother has dementia and has very limited mobility. I've made several phone calls to managers at the service only to be given the runaround. It's been a few months of hell for myself and my family just to try and make a safe environment for my mother.”

Under the Care Act 2014, local authorities have a duty to identify carers. They should also provide information, advice and carers assessments, to ensure that support is given when assessed as needed, including respite or short breaks.

While our local authority assurance work has identified some good initiatives, more could be done to proactively identify and support unpaid carers:

- Carers assessments were available, but the benefit of these assessments was not always clear, which could affect take-up. Carers described them as hard to access and there were digital and language barriers to access.
- The offer and take-up of respite care varied between authorities. Some people reported that respite care was not flexible and didn’t meet their needs.

A Dementia Carers Count survey highlights how over three-quarters of dementia carers, who are looking after a spouse, partner or parent, have no alternative care plan in place for when they can't care for them – for example, should they need to access care and treatment themselves. The survey also reported that 85% of unpaid carers of people with dementia have reached crisis point, with 52% stating they receive no support at all.

A 2024 Alzheimer's Society survey also showed that only 9% of carers had been able to access dementia-specific respite care.

What helps to make sure family and carers are supported?

Good dementia care ensures that family and carers are listened to and included in all appropriate care discussions – especially when family members are moving into care homes.

For example, when a person with dementia goes into a care home, this can be a crisis point, and families and carers can internalise senses of failure.

Services that appreciate this, and provide good dementia-aware care, can have a hugely positive impact on carers and families.

Quote from Give feedback on care:

> "The team have allowed us to be his family again. His wife is able to continue being his wife and his daughters able to be his daughters again, rather than his carers. So, we are able to appreciate and concentrate on the special moments we have left together."

The importance of good communication was reflected in our analysis of outstanding care homes that mainly cared for people with dementia. Inspectors noted that communication between providers, people who use the service and family members was often exceptional, and there were open channels of communication with carers and relatives to gather feedback about the home to improve and enhance the care people received.

Extract from a CQC inspection report:

> “A relative commented, ‘In our experience the management is very good. Communication is excellent and when we have needed to highlight any issues, we have been listened to and actions have been taken. These are then regularly reviewed and communicated back to us.”

Good dementia care services also recognise the need to provide space for carers to step back from their caring responsibilities and socialise with people with shared experiences.

From a former care home manager at a focus group with CQC inspectors:

> “We noticed there were quite a few family members that were really struggling… We set up a small group in a quiet lounge where we would give them afternoon tea once a month. Often the chat was nothing about dementia or their loved ones… went from introductions to actually, what was good on TV last night.”

Where services were not able to provide direct support for carers, they signposted them to external support agencies effectively. One example of this was signposting carers to the Dementia Diaries, where carers and people with dementia could engage with others to share their personal experiences and tips.

In our analysis of the initial assessments from our local authority assurance work, we found that the voluntary sector was often used to provide services for unpaid carers. It was noted this relied on funding, charitable donations and people volunteering to be provided consistently.

Extract from a local authority assessment report:

> “The voluntary sector was seen as a key partner in helping deliver better outcomes for people, including unpaid carers, which contributed to the range of activities that

> people told us they accessed.”

Inequalities

What is the impact of health inequalities for people with dementia?

The challenges described throughout our report highlight some of the ways that people with dementia can have a poorer experience of health and care.

Key stakeholders we engaged with for this strategy told us inequality was a root cause of issues facing people living with dementia. Persistent misunderstandings and stigma associated with dementia can lead to inequalities in how care is delivered and commissioned. They said health inequalities prevail from prevention right through to people’s experience of living with the condition.

These inequalities are discussed in an Office of Health Economics review. This suggests that there are more than 100 inequalities that have an impact on people with dementia and their carers. Issues identified include location, deprivation, socioeconomic status, age, culture, ethnicity, and access to and experience of diagnosis and healthcare.

Some of these findings are reflected in the 2023 Adult inpatient survey for example, which found that people with dementia or Alzheimer’s reported poorer experiences for almost all questions. This included:

- being more likely to feel they were not treated with sufficient respect and dignity
- feeling less involved in their care
- being less likely to feel hospital staff took their individual needs into account.

Analysis of Give feedback on care comments showed there were some potential risks to people being treated as individuals and to equity in access, experience and outcomes – for example, in terms of access to GPs:

> “I can’t organise my thoughts well enough to do telephone calls and can't usually remember the outcome. No thought is given to the needs of people with dementia, for example I can't use the e-consult or the electronic system for booking appointments.”

Combined impact of dementia and other protected characteristics

We commissioned research, Rapid literature review: inequalities in dementia, to identify why some people with dementia get better care than others in care homes.

The research concluded that when a person has dementia, health and care providers and staff should be aware of a number of considerations that ‘intersect’ or have a combined impact with each other. This includes needs related to another protected characteristic under the Equality Act 2010, such as other disabilities, ethnicity and sexual orientation. For example:

- Previous negative experiences of stereotyping or discrimination from health and care services may be re-lived, particularly as a person’s dementia progresses, which can result in anxiety, mistrust and poor engagement.
- A person who loses cognitive function through dementia may be confused about their gender identity, feel they need to hide their sexual orientation, lose English language skills (where it may not be their first language) or use non-verbal behaviour that is specific to their culture, community or previously learned coping strategies.

Despite the importance of being aware of these intersections, analysis from our provider information return indicates that providers do not always consider the combined impact of dementia and other protected characteristics. Answers to the question about what adult social care services have done to meet the needs of people with protected characteristics were generally of poor quality. Dementia was acknowledged as a 'disability' and addressed in terms of ensuring accessibility. However, any intersection with other protected characteristics was rarely acknowledged, other than to mention available equality and diversity training and support to access places of worship. There were few person-centred examples that addressed any intersectionality, especially with 'race' and 'sexual orientation'.

Our Culturally appropriate care resource contains examples and good practice to help care providers think about different ways people's culture might affect the way they wish to receive their care and support.

How are providers and systems tackling inequalities?

This report highlights some of the ways that services are trying to address the health and wellbeing inequalities experienced by people with dementia in using health and care.

A fundamental finding from our Dementia Strategy work so far is that good quality care needs to be personalised to meet the needs of people with dementia from equality groups protected under the Equality Act (2010) – one size does not fit all.

To do this well, staff need to have the time and space to have early and regular conversations with people using the service as well as their family and those closest to them. This enables people to be better understood when staff have the courage and confidence to ask sensitive and complex questions, and to not assume certain needs, likes or dislikes based on personal characteristics.

Person-centred care plans are particularly powerful when supported by thorough and balanced risk assessments, which have the needs of the individual at the core and support their fundamental human rights. This approach requires collaboration between the person with dementia, family members and staff.

While we acknowledge above that it is an area of limited awareness, some providers are acknowledging the combined impact of dementia and protected equality characteristics, such as disability, ethnicity and LGBT+, and responding to people’s needs.

Our inspection reports of outstanding adult social care services highlight how some providers have been sensitive to the cultural needs and traditions of the people they cared for. For example, because people with dementia can lose interest in food, potentially leading to weight loss and increased frailty, the following extract shows how respecting the culture and preferences of a person with dementia can support them to eat well.

Extract from a CQC inspection report:

> “Staff ensured people were able to follow culture and traditions that were important to them. For example, the home's head chef worked closely with a person and their family to develop a personalised menu, which reflected the person's Hindu culture and beliefs. The head chef accompanied the person and their family to a local Indian food shop where the person chose their preferred vegetables and spices for inclusion on their menu.”

Care staff who can culturally connect with the people they care for can be of vital importance to overcome communication issues, and potential barriers to equality, brought on by dementia. Through our analysis of provider information returns we found, for example, either a member of staff would learn expressions from someone’s preferred or first language or a care worker would be provided that had a connection to a person’s cultural background.

Adult social care provider information return:

> “We have a lady who is Welsh (she has dementia). We have worked closely with her family to learn some key Welsh words and phrases as she primarily speaks English, but will revert to Welsh if agitated or tired. This ensures the staff can communicate effectively with her.”

In relation to culture and beliefs, in a few adult social care provider information returns, providers acknowledged the impact dementia can have on practicing a religion or faith. These providers recognised that a person-centred care approach was needed to ensure that religious beliefs continue to be respected, despite dementia impairing the ability of a person to always remember or practice their faith.

Adult social care provider information return:

> “Staff respect the wishes of the resident’s specific religious beliefs. An example is a resident who was a Jehovah witness but had dementia so forgot at times his beliefs. Staff made sure his needs were met by not involving him in Christmas activities and his family were very grateful for this.”

Providers have also told us about how they consider the intersections between dementia and other protected characteristics in the education of their staff. For example, we heard about toolkits to support people with dementia from ethnic minority groups. Care homes and homecare providers commonly reported attending specialist LGBT+ dementia training and workshops.

Adult social care provider information returns:

> “The management group were fortunate to have received training from an LGBT+ dementia expert, which gave us compassionate insight and knowledge, with an awareness to understand, empathise with individuals, and feel confident to support

> our customers.”

> “The staff got the opportunity to talk about scenarios of a person who had transitioned and had dementia and so forgot about their journey. They asked questions about medication management and refusal of medications and the effect on the body medically. It increased our awareness and appreciation of the struggles that people from LGBTQ+ communities have needed to face over the years.”

Acknowledging the combined impact of dementia and protected equality characteristics

Example from the commissioned Rapid literature review: Inequalities in dementia:

A man kept leaving his care home. It became apparent that he was going outside to urinate. There were issues around him using the toilet and he was getting very distressed. Through [guided] life story work, the staff were able to see that this man believed that he was in 1940s/50s rural Punjab, where you went into the fields to go to the toilet. So, there was a conversation within the care home about how the staff could create a safe space for him, rather than making him use a toilet or stopping him from getting fresh air.

Example from National Care Forum, Dementia care and LGBT communities: A good practice paper:

Sue was diagnosed with Alzheimer's Disease and moved to a residential care home. At the home, Sue started to refer to herself as Cliff. Sue would increasingly become distressed at her appearance and physicality. The care home managers had no contact with Sue's family or awareness of her medical history, so they were unaware she was a trans woman. A worker at the care home asked a local charity for advice on how to remain sensitive to Sue's gender identity. A partnership was set up to support Sue's needs, which included care home staff, the GP service and local voluntary organisations. Awareness training on trans identities was also organised for care home staff. As Sue's dementia progressed, staff were able to offer her appropriate support, knowing that their approach was tailored to her needs.